Evaluating a Dignity Care Intervention for palliative care in the community setting: community nurses' perspectives

JCN Journal of Clinical Nursing

Evaluating a Dignity Care Intervention for palliative care in the community setting: community nurses' perspective

Journal:	*Journal of Clinical Nursing*
Manuscript ID	JCN-2016-0894.R2
Manuscript Type:	Original Article
Keywords:	Palliative Care, Evaluation Research, Focus Groups, Community Nursing, Caring Intervention

Abstract

Aim and Objectives. To evaluate a Dignity Care Intervention (DCI) provided by community nurses seeking to address dignity concerns for people with advanced and life limiting conditions

Background. Evidence would suggest that dying people fear a loss of dignity and a central focus of palliative care is to assist people to die with dignity. Whilst community nurses have a key role to play in the delivery of palliative care, specific interventions for dignity are lacking.

Design. A mixed methods study using online survey and focus group interviews and thematic analysis to examine data.

Methods. 24 community nurses implemented the dignity care intervention for people with advanced and life limiting conditions were recruited from four pilot sites across Ireland. Four focus group interviews and on line survey were conducted between March and June 2015

Results. The community nurses found the DCI useful. It helped the nurses to provide holistic end of life care and assisted in the overall assessment of palliative care patients, identifying areas that might not otherwise have been noted. Whilst it was a useful tool for communication they noted that it stimulated some emotionally sensitive conversations for which they felt unprepared.

Conclusions. Implementing the DCI in practice was challenging**.** However, the DCI facilitated holistic assessment and identified patient dignity related concerns that may not have been otherwise identified. Further support is required to overcome barriers and enable dignity conserving care

Relevance to clinical practice. Ensuring dignity is a key aspect of palliative and end of life care; however community nurses may not feel equipped to address this aspect of care. Implementing a dignity care intervention can assist in identifying patient dignity related concerns and provision of holistic care. Community nurses need more training to assist in difficult conversations relating to dignity and end of life care.

Word count: 297

WHAT DOES THIS PAPER CONTRIBUTE TO THE WIDER GLOBAL COMMUNITY?

- Globally, ensuring dignity is considered a core element of quality palliative care; however, it is unclear whether a DCI intervention has an impact in practice. This study adds to the discourse on dignity as a core concept for palliative and end of life care.
- Palliative care has largely been linked with cancer, however this DCI adds to the body of knowledge moving palliative beyond cancer, seeking to address the global issue of ageing, chronic illness and frailty.
- Whilst the barriers to implementation of DCI intervention are similar across different global contexts, cultural aspects related to discussions on death and dying need consideration.
- This study also contributes to the wider discussion on the generalist versus specialist applications of palliative care

Key Words

Dignity, palliative care, community nursing; evaluation; mixed methods

INTRODUCTION

According to the World Health Organisation palliative care seeks improve the quality of life of patients and their families facing life-threatening illness,

> "*through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems"* (WHO, 2002).

In recent years, there has been increasing debate globally that the scope of palliative care should be broadened and provided much earlier in the disease trajectory for both malignant and non-malignant conditions, ensuring the provision of good quality palliative and end of life care for all (WPCA, 2014; WHO 2014). Evidence suggests that the majority of people (60-67%) would prefer to die at home (Van Rensbergen et al, 2006: Gomes et al 2010), nevertheless data would indicate that the majority of deaths (48%) continue to take place in acute hospital settings (McKeown, 2010). The importance of care at home was further noted as important in a recent research priority setting survey for palliative and end of life care in the UK (PeolcPSP, 2015). Therefore strategies to improve the delivery of palliative care in the community context are essential to addressing patient and family expectations at a critical time point.

BACKGROUND

Palliative care is recognised as a valued and important role for the community nursing (Dunne et al, 2005; Walshe & Luker, 2010). This comprises care often provided by generalist community nurses (CN), supported by more specialist palliative care nurses, dependent on the complexity and needs of the patient and family (Andrews and Seymour, 2011). Internationally community nurses may often be referred to as home care nurses, whilst in the United Kingdom, registered nurses who provide care in peoples' homes are referred to as

district nurses. Within Ireland, the community nurse (public health nurse PHN) works through a population based lifespan approach which includes patients and families with palliative and end-of-life needs, and those with chronic, life-limiting illness and frailty. A recent report on public health nursing in Ireland, noted that whilst PHNs have varied links with palliative care services, they retain responsibility for assessing and meeting palliative care needs within the community setting (Office of the Nursing and Midwifery Services Directorate ONMSD 2012).

Burt et al (2008), in a focus group study with district nurses in the UK, reported that community nurses provided a key role in the assessment, planning, co-ordination and provision of care for the dying patient. A qualitative study exploring the role of the district nurse in the UK, found that district nurses have a key role in breaking bad news around the transitions to dying (Griffiths et al, 2015). It was acknowledged however, that this work is particularly complex due to the home context, with a recognised need for further training. Furthermore, Brazil et al (2005) noted that, in Canada, access to community nursing was a positive factor in achieving a home death. Evidence however, suggests that community nurses feel less prepared to deal with psychological aspects of palliative and end of life care (Walshe & Luker, 2010) and may actually employ active avoidance strategies (Griffiths et al, 2010).

Dignity is a concept that pervades health policy, practice and biographical accounts of dying (Anderburg et al, 2007). It is multifaceted and complex with various definitions in the literature, potentially contributing to a sense of confusion when applying and implementing dignity interventions in practice (Jacelon et al, 2004; Guo & Jacelon, 2014; Pringle et al 2015). The need to provide care which is both responsive and supportive to individualised

need is evidenced within the wide body of literature which associates the concept of a good death as one with dignity (Allmark 2002, Yalden & McCormack, 2010;,; Guo and Jaceolon, 2014). In addition, human dignity can also be viewed as an essential value for nursing practice, reflected in International Council of Nurses (ICN) Code of Ethics (Coenen et al, 2007).

An empirically based model of dignity, with a particular resonance for palliative care, has been developed addressing a broad spectrum of concerns inclusive of physical, psychological, social, existential and spiritual sources of distress (Chochinov *et al.* 2002a) This dignity model comprises three main domains; Illness related concerns; Dignity Conserving Repertoire and Social dignity Inventory. According to Chochinov (2002), people experiencing end of life care fear loss of dignity more than anything else and that what defines dignity for the individual patient and his or her family is unique. Therefore, dignity conserving care does not just comprise what one does with or to the patient but also how one views the patient in their humanity (Chochinov 2002b). Various dignity care interventions have been developed based on this work. These include Dignity Therapy, the Patient Dignity Inventory (outlined below) and the Patient Dignity Question (PDQ). The PDQ asks the question: "What do I need to know about you as a person to give you the best care possible?" A recent Canadian study sought to evaluate the impact of the PDQ intervention on patients and families (n=126) and health care providers (n=137) within three palliative care inpatient units. It was found that 90% of the health care providers indicated that they learned something new from PDQ; that 64% that they were emotionally affected by the PDQ and 44% considered that it influenced their care. The authors acknowledged potential limitations in terms of generalisability beyond palliative populations and concerns regarding the self-selection of the health care provider sample. Nevertheless, it can be argued that the study

provides a good starting point for further inquiry into matters pertaining to dignity and personhood.

Dignity Care Intervention (DCI)

The DCI, developed from this empirical model of care, a systematic review of the evidence (Johnston et al, 2015) and previous research (Johnson 2010, 2012) is designed to enable the community nurse to identify the patients' key concerns, provide person centred holistic care and seek to conserve the dignity of people nearing the end of life. The DCI is comprised of a series of stages or component parts (see Figure 1).

Please insert figure 1.

Firstly, stage one involved an educational day, workshop and the provision of an instruction manual. Stage two focused on identifying key concerns from the patients viewpoint using an adapted version of the Patient Dignity Inventory (PDI), a validated tool to assess various facets of dignity (Chochinov et al., 2006; Chochinov et al., 2008) (see figure 2). The PDI is a novel screening instrument that seeks to assess different sources of distress for people with life limiting illness. It has been validated in multiple languages and applied to various palliative care settings and studies globally (Albers et al, 2013; Hall et al, 2013; Sautier et al, 2014). A recent study in the USA noted that the PDI helped assisted clinicians in the oncology setting identify dignity related distress and it helped to disclose information that they were previously unaware of, enabling timely and targeted therapeutic responses to patients' concerns (Chochinov et al 2012).

In the present study, patients were asked to consider which issues, out of a possible 26 items, were most important to them and problematic. Items were rated from 1 (not a problem) to 5

(an overwhelming problem). Any items scored 3 or more were considered as a problem for the patient and, therefore, a concern to be dealt with by the nurse. Reflective questions were then used to explore the identified issues further. Finally, care actions were examined in discussion with the patient. The inclusion criteria for patients were that they were living at home with a chronic life-limiting condition. In total, twenty seven patients completed a DCI tool and eighteen were subsequently interviewed regarding its use. The reasons for non-interview included death; (n=2) admitted into hospice care (n=2), declined to be interviewed (n=3), tool returned with no accompanying details (n=1) and not available for interview (n=1). Of the eighteen patients, the majority were aged 75-84 years (n=10); lived with a partner (n=10); and had various diagnoses including cancer (n=6); COPD (n-4); Frail elderly (n=3); multiple sclerosis (n=2); Parkinson's disease (n=2) and heart failure (n=1).

This paper specifically explored community nurses' perception of using this DCI in practice in an Irish context.

AIM

To evaluate a DCI intervention delivered by community nurses to help conserve the dignity of people with advanced and life limiting conditions including the frail elderly in community settings. Specific objectives were to:

- Explore community nurses' perceptions on the content and use of the DCI
- Examine potential barriers and facilitators to successful implementation and integration into community nursing practices for patients with advanced and life limiting conditions.

METHODS

A mixed methods sequential exploratory mixed methods approach was adopted which included collecting and analysing qualitative data followed by a quantitative phase (Creswell & Clark 2011). This comprised focus group interviews followed by an online survey.

Setting: Participants were recruited from four pilot sites, comprising two urban and two rural sites in Ireland. These pilot sites were selected owing to comparability in terms of profile and population size (see Table 1).

Insert Table 1 here please

Participants: Community nurses (CN's), who included Public Health Nurses and Community Registered General Nurses, were invited by their Director of Nursing to participate in the project. Dignity champions and co-facilitators were also identified to aid the implementation of the project in practice. The total population of community nurses working in these pilot sites and locality areas were invited to participate in a six hour 'train the trainer' education day on the use of the DCI alongside two three hour interactive workshops focused on examining the practical application of the DCI tool, explored through the use of role play and case studies. In total fifty four community nurses (comprised of both Public Health Nurses n=24 and registered General Nurse n=30), attended the education sessions. It was found that education on both palliative care and the dignity intervention improved knowledge and understanding and the overall application of the DCI to practice. The overall evaluation phase of the intervention employed four focus groups (n=24) and an online survey (n=27) with community nurses who had participated in the implementation of the tool in practice. The inclusion criterion was that the participants were required to have attended DCI education session and participated in the implementation of DCI tool in practice. Data collection took place between March-June 2015.

Data Collection

Following the implementation of the Dignity Care Intervention in practice for a period of six months all participating community nurses were then invited to attend a focus group interview (one in each pilot site area) followed by an online survey. The focus groups took place at either the local health centre or the Health Services Executive (HSE – national health care provider) local office. A semi-structured interview guide informed by the literature and the aim and objectives for the study was developed. Questions covered the following broad themes: a) the nurses' perceptions of the content and process of delivering the DCI b) potential barriers to successful use of the DCI and c) factors that facilitated the use of the DCI. Two members of the research team facilitated the focus groups (moderator and note taker) and the number in each group varied from 6-10 participants. The length of time for each focus group ranged from 44 to 60 minutes. All focus group interviews were audio recorded and transcribed verbatim. Reflexive notes were also recorded following each focus group. An online survey was developed and adapted from a previous study evaluating an assessment tool in practice (McIlfatrick & Hasson, 2014) and this tool examined: Perceptions of DCI; Potential contribution to practice and Perceived challenges. Expert feedback on the survey tool was obtained from the project steering group. The online survey was distributed to all the nurses who participated in educational workshops (n-54). Twenty seven responses were obtained (50% response rate).

Ethical considerations

Ethical approval for the study was obtained from a University Ethics Committee (LS-13-55-). An information pack outlining the purpose and nature of the study was provided to each participant and they expressed their willingness to participate via the return of a written

consent form. Consent to take part in the study was contingent upon completion and return of the questionnaires. Assurances were provided that no identifiable information about the participants would be included in the study.

Data Analysis

The focus group data was content analysed using the method outlined by Newell and Burnard (2011). This pragmatic approach to thematic content analysis (Table 2) provided clear guidance within six key stages. Further details on the approach are outlined (see table 2). Descriptive statistics were used to describe and summarise the participant characteristics and survey data.

Validity and Reliability/Rigour

All interviews were transcribed verbatim these were then checked for accuracy against the original digital recordings. Primary data analysis was performed by one member of the research team, following which a selection of transcripts were then independently analysed and reviewed. The overall process of data analysis and identification of the core themes were discussed and agreed between the research team.

FINDINGS

Twenty four nurses participated in the focus group interviews. The majority were in age range 45-65 years and had an average of over 20 years clinical experience average age (see Table 3 and 4). Four key themes were identified from the focus group discussions and online survey: (1) Perceptions of DCI; (2) Use of the DCI in clinical practice; (3) Perceived benefits of the DCI and (4) Challenges for DCI. These themes were further divided into categories (see Table 5).

Perceptions of DCI

The CNs outlined their perception of the DCI and the importance of maintaining dignity for their patients. This included aspects such as *"Meeting the person where they are at", "Respecting their wishes", "Maintaining their wellbeing", "Making sure they are comfortable and content with their own wellbeing".* One CN commented that the focus on the DCI enabled patients to be involved in the decision making:

> *"it's very important, it's not someone making the call for them and looking at what their care needs are, rather than what I expect them to be" (FG2)*

Within the survey, respondents were invited to share their perceptions of the DCI. It was found that 76% (n=19) of respondents agreed/strongly agreed that the DCI was useful for community practice whilst 68% (n=17) agreed that it was clear and easily understood. However, 52% (n=13) considered that the tool was too long to complete (Figure 3).

Please insert Figure 3

Use of the DCI in clinical practice

Respondents reflected on the use of the tool in practice and subcategories related to how the tool was implemented and community nurses' concerns about '*opening a can of worms'* were identified.

"Picking and choosing the people too carefully"

With regards to implementation, all the CNs chose to use pilot the tool with clients already in the service. While this was a practical approach for the selection of the clients, it could be perceived as a method of '*choosing appropriate patients'*. As one CN remarked,

> "*I knew (named patient) would be able to talk* (FG Int 2).

It also gave a perspective on how comfortable the CN felt using the tool,

"*It would be easier to identify with people I had known a long time with a chronic illness*" (FG1).

Subsequently, the tool was distributed to patients already known to the CN service for a number of years.

> "*I felt that maybe one way, we were picking and choosing the people too carefully … We were kind of being cautious about who we chose to do it." (*FG 4).

"Opening a Can of Worms"

The idea of patients asking questions around the areas covered by the tool raised some difficulties for the nurses. They felt that once the questions were asked there was a responsibility to follow through any issues that arose. They stressed that it might generate more visits. The idea of opening a can of worms arose throughout all of the focus groups.

> "Once y*ou open that can of worms … you do have to go back, you cannot leave the person hanging with these ideas and they are unfinished. It takes a lot of time".* (FG2).

It was found that whilst the DCI assisted in identifying aspects that might have been expected, such as physical distressing symptoms and functional limitations, it also assisted in identifying psychological concerns for the patients, such as lack of control and concern regarding unfinished business. Nurse respondents to the online survey were asked to consider the potential contribution the DCI tool made to various aspects of their practice in a community setting (Figure 3). 63% (n=15) of respondents reported that the tool had contributed to the assessment for palliative care patients; 67% (n=16) reported to a great/moderate extent that the tool had initiated discussions with patients and carers that would not normally have happened; 59% (n=14) highlighted to a great/moderate extent that the tool had identified areas of assessment that would not normally have been identified; and finally 61% (n=14) reported to a great/moderate extent that the tool initiated new care for

their patient. In contrast, 65% (n=15) of respondents believed that the tool had not or only to some extent contributed to increased links with specialist palliative care in their community.

Please insert Figure 4.

Perceived benefits of the DCI

There were various perceived benefits to using the tool in practice. The CNs highlighted that the DCI tool could open up a discussion about the future need of a patient. For one woman who had complex problems and had previously avoided taking about them, the tool enabled her to verbalise her thoughts and fears. The outcome was that this patient began to give some thought to her future and how she could manage at home.

The nurse commented:

> "*It (DCI) gave her a bit of insight, it made her think about her situation and I think it helped her, it stimulated her to think* (FG 3).

Another nurse noted an example where the DCI helped to highlight problems that might otherwise have gone undetected.

> *"I had one lady, … she said she hadn't got the courage to do it and she used the word courage … it (DCI) made her question a bit more …She was depressed and some of these questions highlighted that" (FG 1).*

Another benefit of the tool was that the nurses considered the tool to have helped to make explicit the work that they do and provided some assistance for their overall assessment:

> "It's *putting into words what we do* (FG 4)
>
> *"I think a lot of this stuff you do on a visit without even thinking about it" (FG1).*

The results from the survey data reinforced the focus group findings. It was found that the majority (75%, n=15) reported that the tool supported communication (e.g. enabling sensitive conversations, allowing people to talk, creating an openness about death and dying), whilst 35% (n=7) of respondents indicated that the tool helped them to gain an insight or greater

clarity into the needs and experiences of the patient and 25% (n=5) stated that the tool supported the assessment process.

Challenges for DCI

Whilst the DCI was intended to be used as an assessment for maintaining dignity, the nurses felt that it would be difficult to use this at the initial interview. Rather, they considered that it was important to have established a relationship prior to using the tool in practice:

> *"You feel you have to establish some sort of relationship before you go in and ask him would he mind doing it"* (FG1).

As in-depth discussions took place with patients, nurses were stretched in dealing with the issues surrounding death. Some of the CNs felt they lacked the skills to talk about these issues. This was reflected as an overall cultural reluctance to engage with discussions on death and dying.

> *"I think it is a cultural thing. Death and dying and talking about it, certainly during my training it was not something that was discussed. A lot of people were not even told their diagnosis"* (FG1).

During the focus group discussion, the CNs cited their heavy caseload as a challenge to implementing the tool in practice. The survey data reported that some of the biggest challenges to using the DCI tool in practice, were lack of time and/or resources (86% (n=18); difficulty in getting buy-in from patients (48%, n=10) and lack of knowledge of the patient (19%, n=4).

DISCUSSION

The findings provide evidence that the community nurses considered that the dignity care intervention was useful in assisting their overall communication with patients at the end of life. The majority of the nurses found that the tool helped them to gain a greater insight into

the needs and experiences of the patient and that the tool was useful as a supplement to the overall assessment process, helping to facilitate conversations about emotionally sensitive issues. The importance of communication cannot be overemphasised. It is recognised that timely and efficient communication is an important component of palliative care, seeking to address patients' needs and preferences (Wittenberg-Lyles et al., 2014, Norton et al., 2013). Of particular note, is the fact that studies involving palliative patients and their families indicated that they expected health care professionals to be expert communicators, with the ability to initiate and share important information (Thorne et al, 2013; Kirk et al, 2004). Furthermore, a recent integrative review of dignity in end of life care, found that communication was a key factor influencing dignity at this time point, alongside demographic, illness and treatment related care factors (Guo & Jacelon, 2014).

Research findings, however, have consistently demonstrated that communication within a palliative and end of life care context is complex (Borreani et al 2012). In recent years, there has been an increased focus on advance care planning for palliative and end of life care. According to Seymour & Horne (2011) advanced care planning (ACP) is a formalised process of communication between patients, relatives and professional caregivers. A recent review of the literature suggests that ACP tools and programs have the potential to improve communication between patients and healthcare professionals, increase patients' quality of life, reduce the use of futile treatments and unnecessary hospital admissions, and ensure the delivery of care in line with patient wishes (Brinkman-Stoppelenburg, 2014). Various programs and tools have been developed, for example the Respecting Choices Programme in the US and Your Life and Your Choices in the UK. It is important, however, that whilst these tools seek to provide for patients preferences and decision making, they also need to take cognisance of patients' core values and overall wellbeing. It could be argued that the inclusion of a tool such as the DCI, designed and developed for and with community nurses,

framed within an overall advance care planning process could assist in ensuring that the core values of patients and caregivers are respected, alongside assisting decision making

It is important that community nurses seek to develop compassionate, individualistic and tailored care to address the increasingly complex physical, psychosocial and spiritual challenges for people at the end of life. This is of particular relevance in light of changing demographics, increase in the number of frail elderly with co-morbidities. A recent Canadian study described and compared the prevalence and patterns of dignity related distress, using the Patient Dignity Inventory (PDI), amongst diverse non-cancer clinical populations. This study included patients with advanced Amyotrophic Lateral Sclerosis (ALS), Chronic Obstructive Pulmonary Disease (COPD), End Stage Renal Disease (ESRD); and the institutionalised alert frail elderly. It was found that whilst overall loss of dignity did not differ significantly across these study populations and were comparable to those previously reported in end-stage cancer (Chochinov et al 2012), the patterns of distress in each of these groups revealed distinct and important insights. For example, in comparison to the other groups, the frail elderly patients were most likely to identify 'not being able to attend to my bodily functions independently' as problematic (Chochinov et al, 2016).

It was found that the community nurses considered that the DCI provided a safe approach to initiating conversations and creating openness for discussions on death and dying. It was noted however, that whilst the community nurses considered that the Dignity Care Intervention was a valuable tool for helping them respond to patients' psychosocial concerns, they expressed that they did not feel prepared to discuss such concerns. This difficulty in managing psychosocial concerns has been noted in the literature over the last decade (Griffiths et al 2010; 2015, Walshe & Luker, 2010). This raises questions about not only

about the role but also the preparedness of the generalist nurse in palliative and end of life care. It is noteworthy that this continues to be an issue despite global developments around the value and role of palliative care alongside the development of palliative care competency frameworks (European Association for Palliative Care (EAPC), EAPC, 2013; HSE 2014). Whilst there have been calls by the European Association for Palliative Care (EAPC, 2013) to move to a place where all nurses, regardless of specialisation, consider a palliative care approach to be a core requirement for practice, the reality is this needs to be supported in practice. Community nurses need guidance and education to address what are not just emotionally evocative but also ethically fraught situations.

Two of the key challenges noted by the community nurses in implementing the DCI intervention were: (1) the need to develop a relationship with patients and their carers and (2) wider workload issues. The importance of the 'relationship' between community nurses and palliative care patients at the end of life is supported and noted within the literature and is a core finding of many studies undertaken in this area (Andrew and Whyte, 2004; Luker *et al.*, 2000;Bliss and While, 2007;Walshe & Luker, 2010; Offen 2015). Questions however exist as to what exactly is meant by having a relationship and few studies have explored this aspect. Evidence from a patient and carer perspective would suggest that familiarity is also important from a patient and carer perspective (Grande et al, 2004). Therefore, it can be suggested that whilst a focus on 'relationships' can assist in the overall provision of care, there are still questions about whether this has any direct therapeutic outcome for patients and families. The use of a dignity care intervention is emotionally evocative and it is important that its use. The use of DCI requires thoughtful introduction and time to discuss any potentially emerging issues and to become integrated into clinical care rather than seen as something that is distinct.

The second key challenge in implementing the DCI relates to wider workload issues and this is discussed within the context of this current study. In Ireland, Public Health Nurses are considered as generalists with their role encompassing services to the population from birth to death (Scargill 2015). The nurses reported that this broad client base, which has previously been identified as an problem requiring investigation (Brady et al, 2007), alongside large caseloads, impacted not only on the implementation of the DCI intervention in practice, but also on the nurses' perceived confidence and ability to implement DCI intervention within the context of palliative and end of life care. Similar findings have been noted in other contexts. For example, Dwyer et al (2009) noted that lack of resources, poor organisation, insufficient time, and lack of competence were identified as key factors impacting on the ability to ensure dignity at end of life in a nursing home context

Limitations

There are a number of limitations of the study. First, it was conducted within four pilot sites across Ireland impacting on the generalisable of the findings to the rest of the country. It is important to note however that these pilot sites did represent both rural and urban areas with similar practice populations and numbers of community nursing teams. Second, the sample who implemented the tool in practice can be considered as self-selecting, thus perhaps encouraging participation from nurses with a specific interest in dignity conserving and palliative care. This issue sought to be addressed via the use of the follow up survey approach to ascertain the views of others who may not have used the tool in practice. It is acknowledged that the survey tool was limited in terms of validity and reliability. Despite these limitations, the study provides important insights evaluating the DCI in practice

CONCLUSIONS

This study provides a comprehensive evaluation of the use of the DCI for community nurses. The findings indicate that whilst the nurses considered that the DCI intervention facilitated a holistic assessment and identified patient dignity related concerns that may not have been identified otherwise, there were various practice and system challenges to implementation in practice.

RELEVANCE TO CLINICAL PRACTICE

The DCI is a tool for use in clinical practice by community nurses seeking to provide evidence based care that enhances holistic assessment for patients receiving palliative and end of life care. The findings from this evaluation study suggest that the DCI Intervention is useful for community nurses as it helps to facilitate the opportunity to identify and address dignity related concerns that may not otherwise have been addressed. However, advanced communication skills, support and additional education are required to enable the community nurses to engage in conversations with patients regarding their dignity concerns. This needs to be considered not only within the context of a developing agenda relating to advance care planning but also in the context of increasing numbers of people worldwide living into old age with progressive chronic conditions such as frailty, dementia, and chronic disease. Dignity conserving care is a cornerstone of palliative care and such DCI can seek to address the increasingly complex physical, psychosocial, spiritual and existential challenges for people at the end of life. There is a need for further research to examine the perspective of such an intervention on patients and carers alongside further testing on the transferability and acceptability of the DCI, perhaps in other settings and other conditions.

WORD COUNT 4983

REFERENCES

Albers G, de Vet HCW, Pasman HRW, Deliens L, Onwuteaka-Philipsen BD (2013) Personal dignity in the terminally ill from the perspective of caregivers: a survey among trained volunteers and physicians. *J Palliat Med*. 2013 Sep; 16(9):1108–14. doi: 10.1089/jpm.2012.0307 PMID: 23941564

Allmark P.(2002) Death with dignity. *Journal of Medical Ethics*; 28: 255– 257.

Anderberg P, Lepp M, Berglund AL, (2007) Preserving dignity in caring for older adults: a concept analysis. *Journal of Advanced Nursing*; 59: 635–643.

Andrew J. & Whyte F. (2004) The experiences of district nurses caring for people receiving palliative chemotherapy. *International Journal of Palliative Nursing* **10,** 110-118.

Andrews, N., & Seymour, J. (2011). Factors influencing the referral of non-cancer patients to community specialist palliative care nurses. *International Journal of Palliative Nursing*, 17, 35-41

Bliss J. & While A. (2007) District nursing and social work: palliative and continuing care delivery. *British Journal of Community Nursing* **12,** 268-272.

Boot M (2016) Exploring the district nurse role in facilitating individualised advance care planning. British Journal of Community Nursing, 21: 3 144-150

Borreani C, Brunelli C, Bianchi E, Piva L, Moro C, Miccinesi G. (2012) Talking about end-of-life preferences with advanced cancer patients: factors influencing feasibility. *Journal of Pain & Symptom Management*;43(4):739–46.

Brady, AM, Byrne, G. Horan, P. Griffiths, C. MacGregor, C. Begley, C. (2007) Measuring workload of community nurses in Ireland: a review of workload measurement systems. *Journal of Nursing Management*, 15, 481-489.

Brazil K., Bedard M., Krueger P., Abernathy T., Lohfeld L. & Willison K. (2005) Service preferences among family caregivers of the terminally ill. *Journal of Palliative Medicine* **8,** 69-78.

Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. (2014) The effects of advance care planning on end-of-life care: a systematic review. *Palliative Medicine* 28(8):1000–25

Brown H, Ostlund U, Johnston B 2011 Identifying care actions to conserve dignity in end of life care in rural Scotland: Patients, carers, nurses and GPs perspectives. *British Journal of Community Nursing,*16 (5) p.238-245.

Burt J, Shipman C, Addington-Hall J, White P (2008) Nursing the dying within a generalist caseload: a focus group study of district nurses. *International Journal of Nursing Studies* **45**(10): 1470–8

Coenen A, Doorenbos AZ and Wilson SA. (2007) Nursing interventions to promote dignified dying in four countries. *Oncology Nursing Forum* 34: 1151–1156.

Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. (2002a) Dignity in the terminally ill: a developing empirical model. *Social Science and Medicine* 54(3):433-43.

Chochinov HM. (2002b) Dignity-conserving care--a new model for palliative care: helping the patient feel valued. *JAMA,* 287(17), 2253-60.

Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M (2006) Dignity in the terminally ill: revisited. *Journal of Palliative Medicine 9*(3): 666–72

Chochinov HM, Hassard T, McClement S et al (2008) The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of Pain & Symptom Management* **36**(6): 559–71

Chochinov HM, McClement SE, Hack TF, McKeen NA, Rach AM, Gagnon P, et al. The Patient Dignity Inventory: applications in the oncology setting. J Palliat Med. 2012 Sep; 15(9):998–1005. doi: 10.1089/ jpm.2012.0066 PMID: 22946576

Chochinoy H, Johnston W McClement S Hack T Dufault B Enns M , ThompsonG Harlos M , Damant R. Ramsey C , Davison S Zacharias J Milke D Strang D, Heather J. Campbell-Enns Kredentser M (2016) Dignity and distress towards the end of life across four non cancer populations. PLoS One DOI:10.1371/journal.pone.0147607

Creswell J and Clark VL (2011) Designing and conducting mixed methods research. Sage Publications, Thousand Oaks

Dunne, K., Sullivan, K., Kernohan, G.(2005) Palliative care for patients with cancer: District nurses' experiences *Journal of Advanced Nursing*, 50 (4), pp. 372-380.

Dwyer LL, Andershed B, Nordenfelt L, (2009). Dignity as experienced by nursing home staff. *International Journal of J Older People Nursing* 4: 185–193.

EAPC (2013) Core competencies in palliative care: an EAPC White Paper on palliative care education – part 1. European Journal of Palliative Care. 20(2) 86-91

Gomes, B., McCrone, P., Hall, S., Koffman , J., Higginson, I.J. (2010). Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer*, 10, 400. doi:10.1186/1471-2407-10-400

Grande G.E., Farquhar M.C., Barclay S.I.G. & Todd C.J. (2004) Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions. *British Journal of General Practice* **54,** 772-77

Griffiths, J., Ewing, G., Rogers, M., Barclay, S., Martin, A., McCabe, J., & Todd, C. (2007). Supporting cancer patients with palliative care needs: district nurses' role perceptions. *Cancer Nursing*, 30, 156-162.

Griffiths J, Ewing G and Rogers M (2010) Moving Swiftly On." Psychological Support Provided by District Nurses to Patients With Palliative Care Needs. Cancer Nursing33 - I5 - pp 390-397

Griffiths J, Ewing G ,Wilson C, Connolly M & Grande G (2015) Breaking bad news about transitions to dying: A qualitative exploration of the role of the District Nurse. *Palliative Medicine* 29(2) 138–146

Guo Q and Jacelon C (2014) An integrative review of dignity in end of life care *Palliative Medicine* 28 (7): 931-940

Hall S, Goddard C, Martin P, Opio D, Speck P. (2013) Exploring the impact of dignity therapy on distressed patients with advanced cancer: three case studies. PsychoOncology.; 22(8):1748–52. doi10.1002/pon.3206 PMID: 23055454

HSE (2014) Palliative Care Competence Framework Steering Group. Palliative Care Competence Framework. Dublin: Health Service Executive

Jacelon, C.S., Connelly, T.W., Brown, R., Proulx, K., Vo, T., 2004. A concept analysis of dignity for older adults. *Journal of Advanced Nursing* 48, 76–83.

Johnston B, Ostlund U, Brown H. (2012) Evaluation of the Dignity Care Pathway for community nurses caring for people at the end of life. *International Journal of Palliative Nursing,* 18(10), 483-489.

Johnston, B., Larkin, P., Connolly, M., Barry, C, Narayanasamy, M., Östlund, U, et al. (2015) Dignity-conserving care in palliative care settings: An integrative review. *Journal of Clinical Nursing* 24:1743-72.

Kirk P, Kirk I & Kristjanson LJ (2004) What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *British Medical Journal* 5;328(7452):1343.

Ling J (2005) Palliative Care in Irish Nursing Homes: the work of community clinical nurse specialists. International Journal of Palliative Nursing, 11(7), 314-321.

Luker K.A., Austin L., Caress A. & Hallett C.E. (2000) The importance of 'knowing the patient' : community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing* **31,** 775-782

McIlfatrick, S & Hasson F (2014) Evaluating an holistic assessment tool for palliative care practice. *Journal of Clinical Nursing*, 23, 7 10.1111/jocn.12320

McKeown K. (2010) National audit of end of life care in hospitals. *In: Hospice Friendly Hospices on end-of-life care: from the margins to the mainstream.* Dublin, 19th May 2010.

Newell R, Burnard P (2011) *Research for Evidence-Based Practice in Healthcare.* Wiley-Blackwell, Oxford

Norton SA, Metger M, De Luca J, Alexander SC, Quill TE, Gramling R (2013) Palliative care communication: linking patient prognoses, values and goals of care. *Research in Nursing and Health,* 36(6), 582-590.

Ostlund U, Brown H, Johnston B (2012) Dignity Conserving Care at end of life : A narrative review: *European Journal of Oncology Nursing,* DOI 10.1016/j.ejon.2011.07.010 16(4), 353-367.

Offen J (2015) The role of UK district nurses in providing care for adult patients with a terminal diagnosis: a meta-ethnography. International Journal of Palliative Nursing 21(3): 134–41

Office of Nursing Midwifery Services Directorate (2012) Report on current public health nursing services, HSE & ONMSD, Dublin.

Palliative and end of life care priority and end of life care partnership (PeolcPSP) (2015) Putting Patients , Carers and Clinicians at the heart of palliative and end of life care research www.palliativecarepsp.org.uk (accessed 29th July 2016)

Pringle, J., Johnston, B. and Buchanan, D., 2015. Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review. *Palliative Medicine*, *29*(8), pp.675-694.)

Quinn C, Bailey M (2011) Caring for Children and Families in the community: experiences of Irish palliative care community nurse specialists. International Journal of Palliative Nursing, 17(11), 561-567.

Sautier LP, Vehling S, Mehnert A. (2014) Assessment of Patients' Dignity in Cancer Care: Preliminary Psychometricsof the German Version of the Patient Dignity Inventory (PDI-G). J Pain Symptom Manage. 47(1):181–8. doi: 10.1016/j.jpainsymman.2013.02.023 PMID: 23830532

Scargill M. (2015) A week in my . . . public health clinic: 'Generalist nature of our work is what makes it special. *Irish Times,* Jan 20th. Available at http://www.irishtimes.com/life-and-style/health-family/a-week-in-my-public-health-clinic-generalist-nature-of-our-work-is-what-makes-it-special-1.2063089

Seymour J, Horne G. (2011) Advance care planning for the end of life: An overview. In: Thomas K, Lobo B, editors. Advance care planning in end of life care. Oxford: Oxford University Press;. 16–27.

Thorne S., Oliffe J. L., Stajduhar K. I., Oglov V., Kim-Sing C., Hislop T. G. (2013). Poor communication in cancer care: patient perspectives on what it is and what to do about it. *Cancer Nurs.* 36 445–453

.

Van Rensbergen G, Nawrot, TS, Van Hecke, E et al. (2006) Where do the elderly die? The impact of nursing home utilisation on the place of death. Observations from a mortality cohort study in Flanders. *BMC Public Health* ;6:178.

Walshe C, Luker KA (2010) District nurses' role in palliative care provision: a realist review. *International Journal of Nursing Studies* **47**(9): 1167–83.

Wittenberg-Lyles E, Goldsmith J, Small Platt C (2014) Palliative care communication. *Seminars in Oncology Nursing*, 30(4), 280-286.

World Health Organisation (2002) WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/ accessed Jan 2016

World Health Organisaton (2014) Strengthening of palliative care as a component of comprehensive care throughout the life course
WHA67.19. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf accessed Jan 2016

World Palliative Care Alliance (2014) Global Atlas of Palliative Care at the end of Life. WPCA, WHO http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf accessed Jan 2016

Yalden BJ and McCormack B. (2010) Constructions of dignity: a pre-requisite for flourishing in the workplace? *International Journal of Older People Nursing*, 5: 137–147

FIGURES & TABLES

		Population	PHN	RGN
Site 1	Urban	42,254	11	4
Site 2	Urban	34,043	10	3
Site 3	Rural	55,101	15	10
Site 4	Rural	30,868	9	2.4

Table 1: Profile of the Pilot Sites

Figure 1: Stages for Dignity Care Intervention

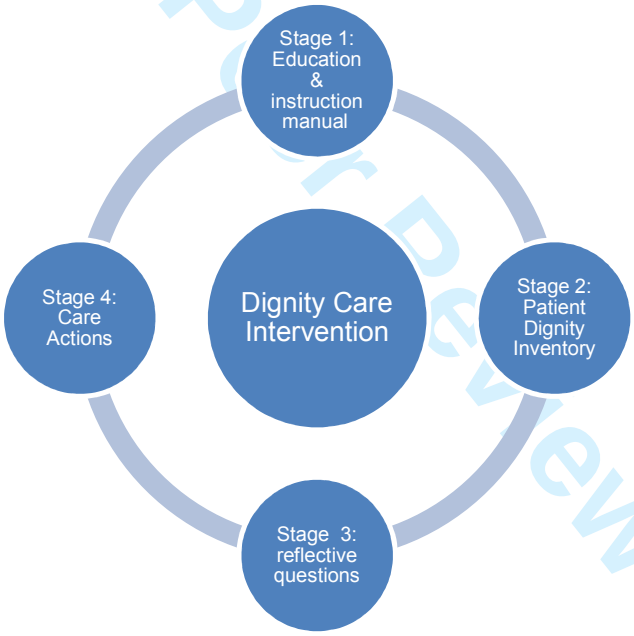

Figure 2: PATIENT DIGNITY INVENTORY

ILLNESS RELATED CONCERNS

1. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea)				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
2. Feeling depressed				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
3. Feeling anxious				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
4. Feeling uncertain about my health				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
5. Worrying about my future				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
6. Not being able to carry out tasks associated with daily living (e.g. washing, getting dressed)				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
7. Not being able to attend to bodily functions independently (e.g. needing assistance with toilet related activities)				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
8. Not being able to think clearly				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem

DIGNITY-CONSERVING REPERTOIRE

9. Feeling that how I look to others has changed significantly				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
10. Feeling like I am no longer who I was				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
11. Not feeling worthwhile or valued				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
12. Not being able to carry out important roles				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem

13. Feeling that life no longer has meaning or purpose				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
14. Feeling that I have not made a meaningful and/or lasting contribution in my life				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
15. Feeling that I have unfinished business				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
16. Feeling that I don't have control over my life				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem

17. Not being able to accept the way things are				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
18. Feeling like I am no longer able to mentally cope with challenges to my health				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
19. Not being able to continue with my usual routines				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
20. Concern that my spiritual life is not meaningful				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem

SOCIAL DIGNITY INVENTORY

21. Feeling that care needs have reduced my privacy				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
22. Not feeling supported by my community of friends and family				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
23. Not feeling supported by my health care providers				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
24. Not being treated with respect or understanding by others				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
25. Feeling that I am a burden to others				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem
26. Worries about how illness or death will affect my family or friends				
1 Not a problem	2 A slight problem	3 A problem	4 A major problem	5 An overwhelming problem

Table 2 : Thematic Content Analysis Process (adapted from Newell and Burnard, 2006,)

Stage 1	Notes or 'memos' are made of each interview reflecting what was talked about.
Stage 2	Following transcription interview transcripts are read through and notes made in the margin in relation to general themes that are appearing.
Stage 3	The transcripts are read through again and all aspects of the content are described using 'open codes'.
Stage 4	Collect all of the categories together and combine/ use one heading where there are two that are similar.

Stage 5	Return to the transcripts with the shortened list of codes. Work through the transcripts and allocate each part of the text to the category which it reflects.
Stage 6	Data is organised into the basis for writing and reporting the qualitative findings.

Table 3: Demographic Profile of Focus ~Group Participants

Gender	
Male	0
Female	24
Age Range	
25-45	5
45-65	19
Staff Grade	
PHN	19
Community RGN	5
Length of time working in community setting	
1-5 years	7
6-10 yrs	5
11-15 yrs	9
More than 15 yrs	3

Table 4. Demographic Profile of survey respondents (n=27)

Gender	Female (100%, n=27)
Age	25-34yrs (4%, n=1) 35-44yrs (32%, n=8) 45-54yrs (36%, n=9) 55-65yrs (28%,n=7)
Current area of practice	Public Health Nurse (73%, n=16) Community RGN (27%,n=6)
Length of time working as a nurse	6-10yrs (8%,n=2) 11-15yrs (12%,n=3) 16-20yrs (16%,n=4) 20+yrs (64%,n=16)
Working arrangements	Full-time (68%,n=17) Part-time (24%, n=6) Other (8%,n=2)
Educational qualifications	Certificate (42%,n=11) Diploma (38%,n=10) Degree (35%, n=9) Masters (19%,n=5)

Table 5: Key Themes

Themes	Categories

Perceptions of DCI	Respect Recognising the person
Use of the tool in practice	Picking and choosing people Piece of paper and tick box Opening can of worms
Benefits of Tool	Making work explicit Identifying patient concerns
Challenges of using tool	Instrumental Factors: Length of tool; Initiating difficult conversations Feeling unprepared Organisational factors: Workload, resource and role implications

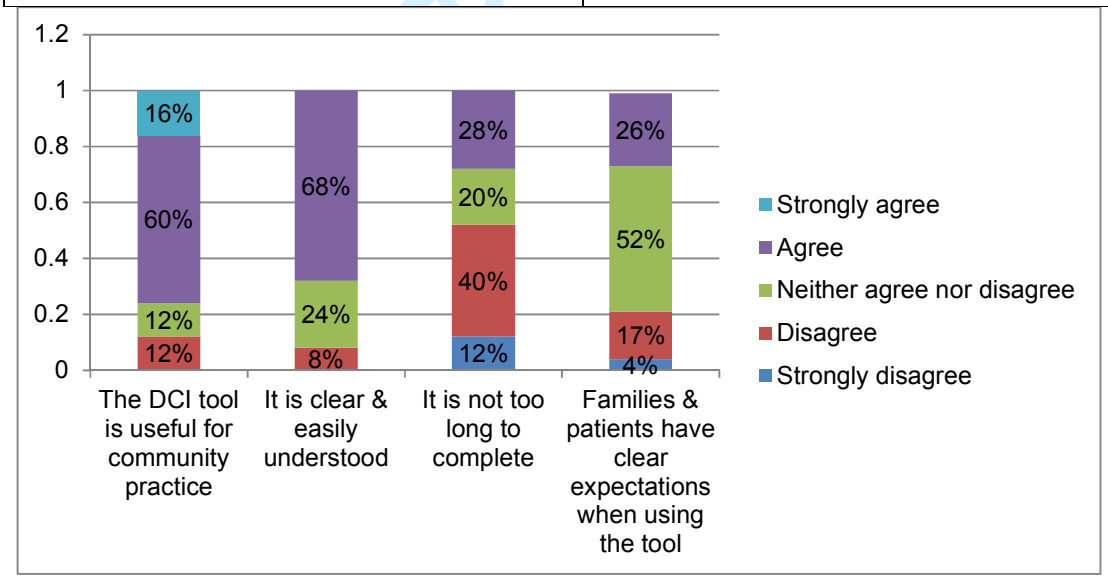

Figure 3: Perceptions of DCI Tool

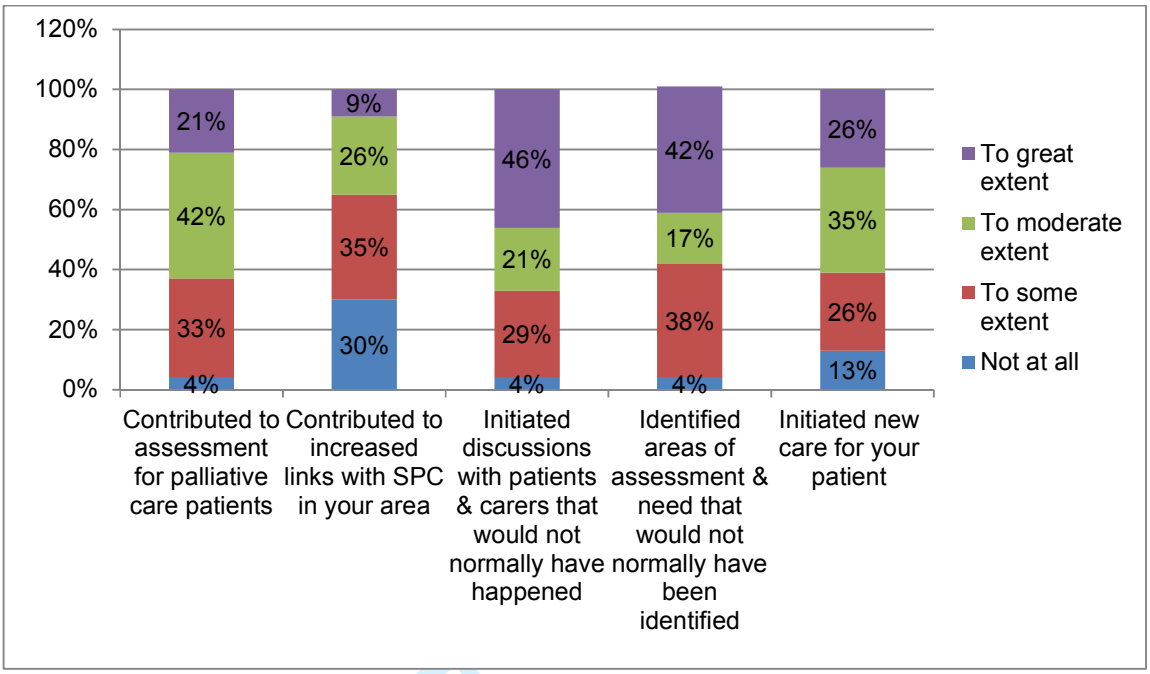

Figure 4. Contribution the DCI to practice